

DISABILITY AND DEVELOPMENT IN KOSOVO: THE CASE FOR COMMUNITY BASED REHABILITATION

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ABSTRACT

After completion of most of the planned reconstruction work, Kosovo is now in the process of rebuilding civic and public life which was substantially disrupted during the war of 1999, apart from the disruption caused in the previous ten years of a parallel system under Serb Milosevic's rule. Health and social issues are receiving fair attention with emphasis on principles of equality and equity. Disability issues are amongst those that received particular attention from the international community.

Reducing inequality between sections of society requires changes in attitude, creation of sustainable structures, introduction of legislation, policies and working strategies. Equally important is providing services for the vast unmet needs of disabled people, using appropriate approaches that enhance self-capabilities and create a feeling of ownership. This paper argues the case for a more comprehensive approach to disability such as community based rehabilitation (CBR) to be introduced in Kosovo where local people and users of services are involved in the rehabilitation process actively. Employing a participatory approach to rehabilitation such as CBR, in reality however, is a challenging task, given the historical context of Kosovo under a communist regime with limited grassroots participation.

DISABILITY AND DEVELOPMENT

Although community based rehabilitation (CBR) has been known as a strategy for rehabilitation, in recent years, it is being also used as a vehicle for creating social change and as a means for political mobilisation of disabled people at grass-roots level (1). These aspects have been neglected in most CBR work in Kosovo. It is important for emerging disability organisations in Kosovo to recognise these issues, for them to achieve their vision of a disability movement with nation-wide membership.

Of late, disability is also considered as a development issue by planners and policy makers in an increasing number of countries across the world (2). Disability and development are closely linked in a cycle of cause and effect, and both are regarded as political issues because the way they are defined by society will influence the measures taken to deal with them. The political implication of this understanding of disability can be seen in Kosovo in the way in which the disability sector has been supported and developed in recent years. Because functional limitation is considered as most restricting to individuals, attention has been directed towards those with physical mobility. Other impairments and disabilities that are not so obvious receive less attention from planners and policy makers although they are as restricting to the concerned individuals as other impairments. National and international initiatives in Kosovo have historically focused on physical and mental impairments, and more recently on other kinds of impairments, employing a medical approach to rehabilitation. Only recently have some international NGOs been involved in policy development, and they support local efforts to set up a task force on disability policy. The association of paraplegic children Handikos, with its 10 community centres and 25 community groups throughout Kosovo, has been the main partner to most international NGOs. Handikos' experience in policy development is still modest and it is expected to produce a Green paper on disability by end of 2001. However, Handikos' experience in physical rehabilitation has been commendable in Kosovo and this will be analysed in some detail in the proposed document.

The current trend of supporting local disability service providers to reach the status of an umbrella organisation and to influence policy are important and needed in Kosovo, but this process should not force premature changes in existing structures. In changing their role, such organisations should not neglect their obligations to service delivery. Drawing from the experiences of other social and political movements in the world including those of disabled people, it is seen that often the needs at the grassroots level generate the impetus for social change and changes in policy. Volunteers at the grass roots level can also lend support to community organisations, strengthening their position as service delivery organisations and justifying another potentially important role of these agencies as advocacy organisations (3). This bottom up approach

from the grass roots has helped to highlight the situation of disabled people in Kosovo, and has proved to be sustainable after overcoming many obstacles so far. It is important that this approach continues at both policy and service delivery levels so that ordinary disabled people continue to feel part of a movement and to extend appropriate support to their leaders when necessary.

APPROACHES TO DISABILITY IN KOSOVO

The complexity of the situation in Kosovo, including the fragile peace process in the region, the repeated clashes between ethnic groups in neighbouring Macedonia which has the potential to develop into a civil war, the increasing number of refugees from Macedonia, many of whom have disabilities, have necessitated the development of different approaches and methods of work. The needs of disabled people have been met through institutional residential approaches provided by the previous regime, specialised medical rehabilitation centres established by both international and local initiatives and of late, community based approaches promoted mainly by international organisations. International involvement in disability issues in Kosovo now focuses on building partnerships with local organisations such as Handikos and its network, in five major areas.

1. Assistance in service delivery

This approach was prominent in Kosovo especially after the war. This kind of assistance is provided directly to local disability organisations or to disabled individuals. Different kinds of organisations are involved in service delivery, including those that serve a single group such as landmine victims, those that have a special project for disabled people as one of their range of activities, and those that include disabled people as part of the group of disadvantaged persons such as the poor, minority groups, unemployed, and so on.

2. Capacity building

This kind of support started after the war, in line with the United Nations Interim Mission in Kosovo (UNMIK) ideals of building a sustainable society and effective organisations. There are a number of international NGOs working on capacity building of local disability organisations such as Handikos, deaf clubs and others. Support for capacity building includes two aspects. The first is strengthening of management and administrative structure within the headquarters, and of the network of community centres and local groups. The second is support for building a base of knowledge and skills for field staff through training workshops, seminars and follow up visits.

3. Support in policy development

This work was pioneered by some European agencies from 2000 and is in line with the democratisation process promoted by UNMIK and Organisation of Security and Cooperation in Europe (OSCE). It focuses on developing policies for disabled people at the national level in the form of Green and White papers, which will form the basis for legislation on disability subsequently. This is a collaborative effort with Handikos association along with associations of persons with visual and communication impairments. UNMIK had showed interest in supporting policy development but there is still no single specialist person or unit at UNMIK to provide the technical backup to partners involved in this process. It is obvious that partners are motivated to advance the cause of disabled people at the policy level, but it is also clear that technical knowledge is limited in many ways.

4. Support to co-ordination between partners

There are around 300 international NGOs operating in Kosovo, some of whom (approximately 30) work with disabled people in one or more of the above mentioned areas. UNMIK by virtue of their mandate, issues policies and lays down the procedures to regulate the work of NGOs. There is however, a clear lack of co-ordination and co-operation between partners. Potential areas of co-operation could be information sharing, co-ordination in planning activities and their implementation, joint funding when applicable and influencing of policies.

5. Funding support

This includes bilateral and multilateral co-operations, government funds and other forms of local financial support.

Another area for co-operation between partners in Kosovo is research. Planning services for disabled people based solely on reports and outside expertise is not sufficient to gain insights into the situation of disabled people. Proper research practices such as a situational analysis, are missing. Two important areas for the future are policy research and research on social change and community mobilisation.

SHORTCOMINGS IN THE EXISTING STRUCTURE

The humanitarian situation in pre and post-war Kosovo necessitated a quick response on the part of UN and other international agencies to the vast needs of Kosovars, using methods different from what were used in other parts of the world. To prevent starvation, ill health, violence, abuse, and post war complications, a great deal of resources have been invested by the international community (4). However, there have been some limitations in delivering assistance to local people, particularly when working in partnership with local organisations.

In addition to creating an artificial environment in Kosovo which does not seem to be sustainable, international NGOs have also promoted a feeling of dependency and reliance on external help, rather than creation of self capabilities, self confidence or local strength and resources. This happened because the emergency practices have continued until now and the agencies have been slow to adopt a more sustainable approach to community development.

It is fairly easy to identify western influences on Kosovar society, especially in Prishtina. The designer shops, 'high tech' stores and mobile phones are visible everywhere, like in any other western country. Although this may be the situation to aspire for in many underdeveloped countries, the process may have happened too soon and too suddenly in Kosovo, such that the local people are not even able to figure out what is going on around them, what will occur in the near future and how they are going to maintain the same level of living in the future. Creating a free market economy and culture can be important to the development of society, but it should be in the context of local norms, values and traditions. Moreover, market economy needs to also take note of promoting local industries, local capabilities and community wealth. Foreign aid regardless of the political reason, is not in itself sufficient for nation-building, although it may be essential for the development of Kosovar society.

International NGOs have been influential on a smaller scale relating to the disability sector in Kosovo, and have been successful in bringing it to the world's attention. Despite positive contributions to the disability sector, these agencies have also had their limitations. A critical review of the current involvement of international NGOs in disability issues in Kosovo shows that the work was mainly carried out by expatriates, and local capacity building has been limited. Despite the great potential of existing resources in terms of staff, funding, skills and so on, the majority of workers employed by these agencies (locals and outsiders) lack proper qualifications, knowledge and attitudes with regard to disability interventions (5). Their partnership has also focused on Handikos as the main association of physically impaired people and not enough efforts have been made to include other categories of impairments or other organisations and groups. Although other groups of disabled people are represented at a policy level in task force meetings, their voices are not heard and their presence takes the form of representation without active participation. Even the support to develop Handikos as an umbrella organisation has neglected some fundamental issues relating to NGO structure, such as voluntary membership status. Currently individual members of Handikos are those employed at the network, who are considered as volunteers. Their remuneration however, is higher than full time employees of state run services. Existing forms of support to disabled people obviously lack strategic thinking in terms of long term development of Handikos association and its network, apart from the disability sector at large. Creating an umbrella organisation requires different inputs, process and outputs (5).

Overall, work in the disability sector in Kosovo has focused on reactive planning in delivering services instead of a proactive approach to planning. No mechanisms were set up to measure outcomes or to monitor performance. In conclusion, the work to date, remains scattered and ineffective as every partner has their own different and sometimes contradictory approach to disability in Kosovo, method of work and political priorities. Kosovo lacks a comprehensive disability policy starting from definitions and ending with inclusion and beyond. It becomes essential therefore to involve all stakeholders in a dialogue and

consultation process in order to reach a single policy position and plan of action regarding disability issues in Kosovo.

FUTURE DIRECTIONS IN THE DISABILITY SECTOR IN KOSOVO

The timely debate about moving towards a disability and development perspective by the international community in Kosovo, means engaging in politics because the proposed process promotes participation, partnership and empowerment. In a sense, everything becomes political, from terminology to policy to service provision. It does not mean that service provision is ignored in focusing on disability policy and disability politics. But rather, it means a consideration of politics as an underlying principle in service delivery, in line with the ideals promoted by the disability movement and disabled people's organisations.

Active participation, control and ownership by disabled people who are service users are the key issues for the future of the disability sector in Kosovo. This includes their involvement in assessing their needs, making priorities and designing interventions. Involvement in policy making at all levels is also necessary to the development of the disability movement's identity and character. The political insights drawn from the 'disability approach' can also serve as a guiding experience to other oppressed and marginalised groups in society such as ethnic minorities, women and poor people. This can help to facilitate the goal of inclusion of disabled people into society with equal access to services and opportunities in line with a citizenship approach to disability (6). In the long run, inclusion leads to empowerment in the sense that disabled people will realise their potential and get more power over their lives.

Generally speaking, without feedback, the desired impact over any issue can not be ensured. On a more specific scale, development interventions in disability can only be verified and validated when feedback is given and evaluation is undertaken to see whether objectives have been achieved within specified timeframes and levels (7). Many international NGOs have neglected this important aspect of the project cycle and have continued to provide their support based on political grounds, or on requests based on estimated needs by other partners. Very little effort has been made to evaluate previous and existing support or to develop monitoring criteria. Standards for monitoring and evaluation of disability projects are necessary not only for planning services but also for decisions concerning future support. Future investment in disability issues needs to be based on evaluation and proper situational analysis. Any evaluation process should focus on activities and how much they relate to the stated objectives. Quality of service, level of performance, satisfaction of users, and development of the community are some of the parameters to be considered for evaluation. It is crucial to reach a balance between professionals' views and those of service users about the achievements.

In Kosovo, although various training courses have introduced the social model of disability and the CBR approach, their application remains limited. For example, until now, the assessment of disabled children and adults relied solely on a medical model. This only serves to locate disability issues within the individualistic medical understanding and not within its wider societal and political context (8).

TOWARDS A DEVELOPMENT APPROACH TO DISABILITY: THE CBR MODEL

The socio-cultural and economic construction of disability suggests a solution within societal boundaries. Given its developmental nature, the notion of disability can best be addressed under a community development framework such as CBR. CBR is built on four main developmental principles namely, 'minimum approach to assistance', 'participation', 'sustainability', and 'empowerment'. These are discussed below.

When initiating CBR, it is important to reach a balance between outsider support and local contribution. Although most CBR projects world-wide were started by outsiders, there is always room for greater involvement of local people (9). The 'minimum assistance approach' aims at enhancing self-reliance of the local community and utilisation of local resources. This approach involves a partnership with the local community where locals are required to contribute actively as equal stakeholders, and encourages independence and creativity in handling community affairs.

The active 'participation' of the local community including users of services and their families in the rehabilitation process, creates a feeling of ownership and promotes a sense of control over community development initiatives (10). This can be valuable for sustainability of any project. Participation is a never

ending process and the development approach to disability strives to achieve a high level of participation of local people and other stakeholders in all stages of CBR starting from identification of needs and project design, and ending up with evaluation and decisions about the future (11).

'Sustainability' is often the number one concern of any development project, including CBR. It means more than securing enough funding to keep the project running, as it involves skills, human resources and other contextual issues. For planners, sustainability is an ethical issue in the sense that providing services should be guided by thinking of the long lasting effect on the local community and on those who will benefit from the intervention, enabling them to become self sufficient.

Increasingly, CBR initiatives have emphasised the concept of 'empowerment' of those involved in the rehabilitation process, especially users of services. CBR can in fact facilitate the emancipation of disabled people by letting them be part of such a process and thus serve as a political tool which may contribute towards empowerment. Disabled people are often the last on the list to be consulted regarding the way services are delivered to them and their views are often neglected by a strong presence of professionals at all levels (12). Perhaps, the most current controversial issue in disability and rehabilitation is 'power relations' between professionals and disabled people. Historically, professionals and able-bodied people have maintained control over disabled people's lives perpetuating their passivity and contributing to their dependency (8). The latter was one of the reasons for the emergence of the disability movement and de-institutionalisation of rehabilitation services across the world. Debate concerning this move is still growing in Kosovo, but at a slow pace.

There are variations in different societies regarding what CBR means and involves. Applying an imported definition of CBR into a certain context should thus be treated with caution. Successful CBR initiatives are those which take note of 'cultural issues'. This primarily means the way cultural belief systems define and perceive a disabled person, as well as societal attitudes towards that person. A CBR that is based on women as the workforce for example, would not win local support in a male dominated society although women usually end up doing most of the labour required by CBR in most instances. In Kosovo, Werner's 'Disabled Village Children' (13) is widely used as a 'curriculum' for rehabilitation in the community centres of Handikos. Werner's work which has been translated into many languages including Albanian, can be useful in the Kosovar context, but needs to be modified to suit the current state of development in Kosovar society. The philosophy underlying this work nonetheless remains important as it encourages local solutions to local problems employing simple community based technology.

To sum up, CBR aims to mobilise disabled people to achieve their own empowerment (14). The fact that traditional approaches have been unable to reach those in need efficiently and in a cost effective way, has led to the emergence of CBR as an alternative approach. This new approach promotes greater involvement of disabled people in the rehabilitation process and utilises local resources to the maximum level possible, both of which are greatly needed in Kosovo.

Given the complex situation of rehabilitation services in Kosovo in terms of existing skills and knowledge and how they respond to the needs of disabled people, starting a CBR at national level as being promoted by some international NGOs would not be practical. By definition, CBR is based on active local community participation and utilises available resources. Setting up a CBR project requires a different approach which considers quality of services as most important together with reaching wider target groups, ideally through sampling or small scale projects. CBR aims not only to provide rehabilitation services to those in need but also to change attitudes of the local community towards service delivery itself. The ultimate goal of CBR is to make people responsible for their own rehabilitation process and subsequent outcomes.

At present, CBR services in Kosovo are provided by Handikos. Its operation consists of 10 community centres and 25 local active groups with a total workforce of 135 people including those at the headquarters, all of whom are considered as volunteers. The network (community centres and local active groups), are linked with regional co-ordinators who in turn report to the Handikos headquarters. A local active group consists of a field co-ordinator, medical health technician and the person in charge of the group. They are responsible for identification of new cases, registration, referral to community centres and distribution of materials. At community centres there are 2 physiotherapy technicians, a psychosocial worker, a centre co-

ordinator and a driver. Workers at community centres provide physical rehabilitation services (physiotherapy and play activities) to children attending the centres.

There is a need for more appropriate tools to monitor the progress of rehabilitation interventions at community centres. The tools adapted from 'Disabled Village Children' are not sufficiently developed for accurate measurement of performance. Monitoring tools need to answer the following questions: what level of functioning does the disabled person have at present? What targets are to be set for interventions, focusing on ability and not disability? What interventions will achieve the targets, with family involvement in the process? Such information can help in further planning.

CONCLUSION

There are two polarising positions with regard to disability and rehabilitation in Kosovo, namely, rehabilitation as an emergency response, versus rehabilitation as a form of development. Sponsors of the disability sector, including the international community and UNMIK, are moving slowly towards a development approach to disability. Present practices, however, are still biased towards an emergency approach, with little efforts towards capacity building and skills transfer to local partners.

Current practices in CBR are also lacking in contemporary and sustainable methods of work. For example, existing CBR training is medical in nature, and would benefit from a more holistic view of community and inclusive ideals. Disabled people have needs other than medical rehabilitation and these should be assessed and addressed properly, including the needs for education, vocational training, employment and involvement in political life. Although the needs of disabled people across societies are similar in some way, the priorities of disabled Kosovars might be substantially different from other countries due to the particular nature of the society in terms of political, socio-economic and cultural circumstances. Regardless of which country disabled people live in however, they need to have a source of income as a priority to meet their everyday needs (15).

The lack of a clear policy on disability and rehabilitation at Kosovo leads to much diversity in the different players in terms of focus, methods of work and political priority. Setting a common framework of action for policy on disability issues would be particularly relevant in this context. Furthermore, encouraging debate concerning empowerment of disabled people might be one way to bridge the gap between the various players in the disability field. On a larger scale, co-ordination between partners is needed and should be taken forward so that the needs of disabled people are better served. There is also a pressing need to develop 'disability and rehabilitation research' where planning is based on real needs.

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ACKNOWLEDGEMENT

This paper is based on a longer version of a Mission Report on "Disability Sector in Kosovo" produced for Handicap International, France. The researcher was working for Handicap International – Kosovo and was based in Prishtina between December 2000 and June 2001 while writing this report.

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